

An ethical dilemma: How can we authentically represent the voices of disabled children and young people about their views, experiences and choices for participation in recreational activities?

Dawn Pickering, Staff candidate,  
Part time PhD student,  
School of Healthcare Sciences, Cardiff University  
UK Disabled Children's Research Network,  
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- To explore issues around the authentic engagement and representation of disabled children and young people in research.
- Describe how visual methods were used, as part of a multiple comparative case study design.
- The need to anonymise the visual data can lead to a loss of meaning, whilst still revealing some real aspects of their lives.

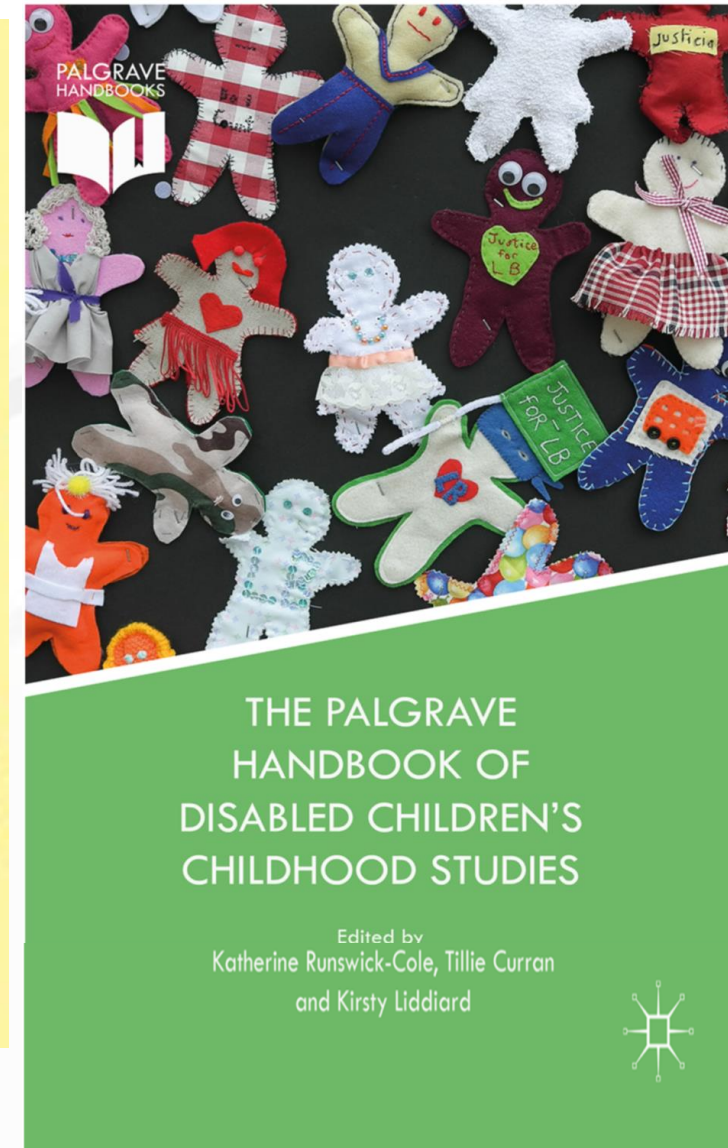
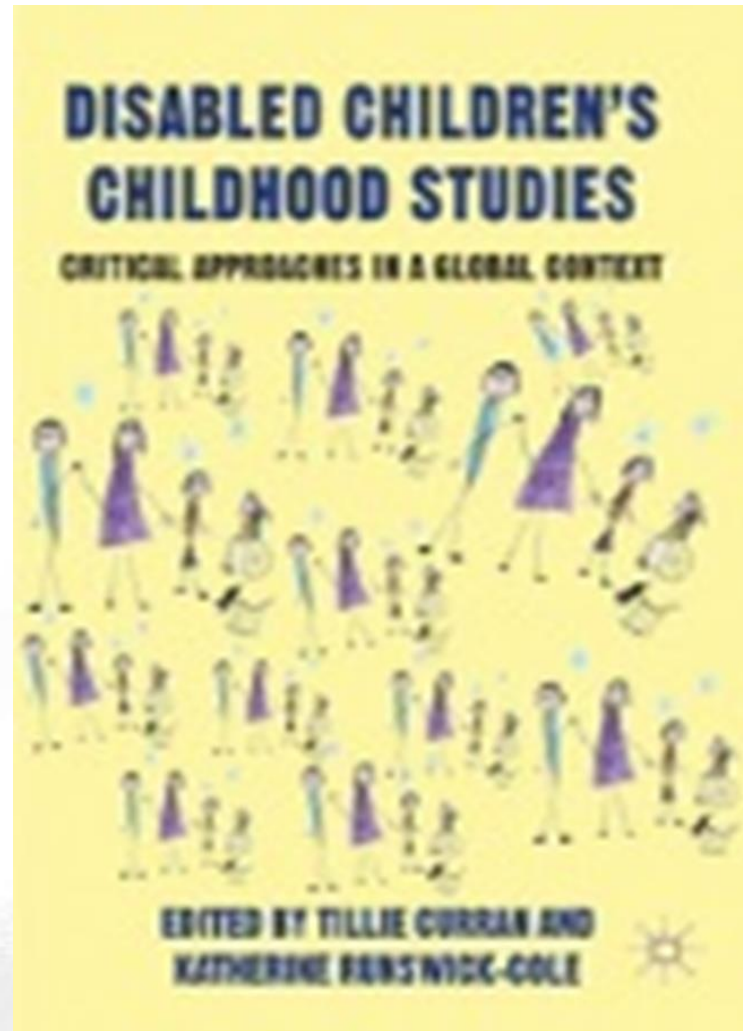


PhD : ‘VOCAL’ study title- “Beyond Physiotherapy: Voices of children and young people with cerebral palsy and their parents about ‘Participation’ in recreational activities.”

- My position as a former children’s physiotherapist- voices of children often missing in treatment choices-‘Rights’.
- Method-Case study design using creative, visual and participatory approaches with disabled children and young people, aged 9-16 years, with walking communication and learning disabilities.
- 7 Case studies, 4 who did participate and 3 who did not.
- Each case included: 2 interviews (some with children and young people, some with parents), 12 weeks apart, a diary of recreational activities recorded and an observation of an activity during this period where non identifiable photographs were taken.



- Disabled children's childhood studies demands **ethical research practices** that position disabled children and young people at the centre of the inquiry outside of the shadow of the perceived 'norms': Re-imagining their futures. Researching '*with*' not '*on*' disabled children and young people.
- Those with most severe disabilities usually excluded from research.





‘Have the right to rest, leisure, play and recreation and to take part in cultural and artistic activities’

<http://www.playwales.org.uk/eng/>



- **Research question**

- How do children and young people with cerebral palsy and their carer's view, experience and choose their level of participation in recreational activities?

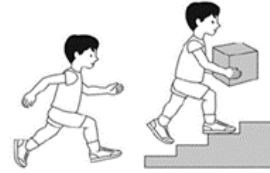
- **Study Aims**

- The 2 aims of this study were to explore participants':
  - Views, experiences and choices for their level of participation in recreational activities, including barriers and facilitators.
  - Perceptions of the effect of their level of participation upon their emotional wellbeing.



- Cerebral Palsy- long term condition affecting motor and sensory control
- Gross Motor Function Classification System (GMFCS)- 5 levels of ability
- Seeking to explore their views, experiences and choices about meaningful participation in recreational activities- less choices
- Little known yet about their emotional wellbeing.

## GMFCS E & R Descriptors and Illustrations for Children between their 6<sup>th</sup> and 12<sup>th</sup> birthday



### GMFCS Level I

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited



### GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.



### GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.



### GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.



### GMFCS Level V

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

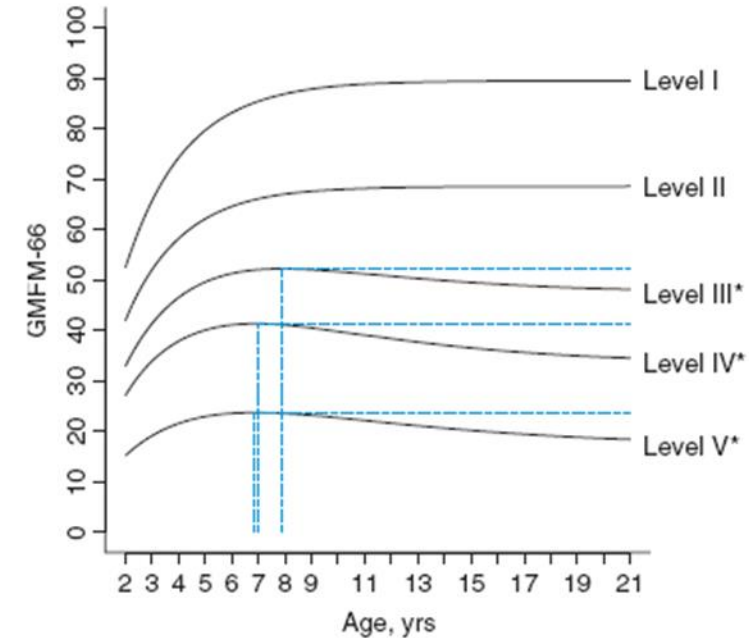
GMFCS descriptors copyright © Palisano et al. (1997) Dev Med Child Neurol 39:214-23  
CanChild: www.canchild.ca

Illustrations copyright © Kerr Graham, Bill Reid and Adrienne Harvey,  
The Royal Children's Hospital, Melbourne

*Palisano et al, 1997; Reid et al, 2011*



- Levels III-V of the Gross Motor Function Classification System (GMFCS)- natural decline
- Children and young people (CYP) with cerebral palsy aged 9-16 years

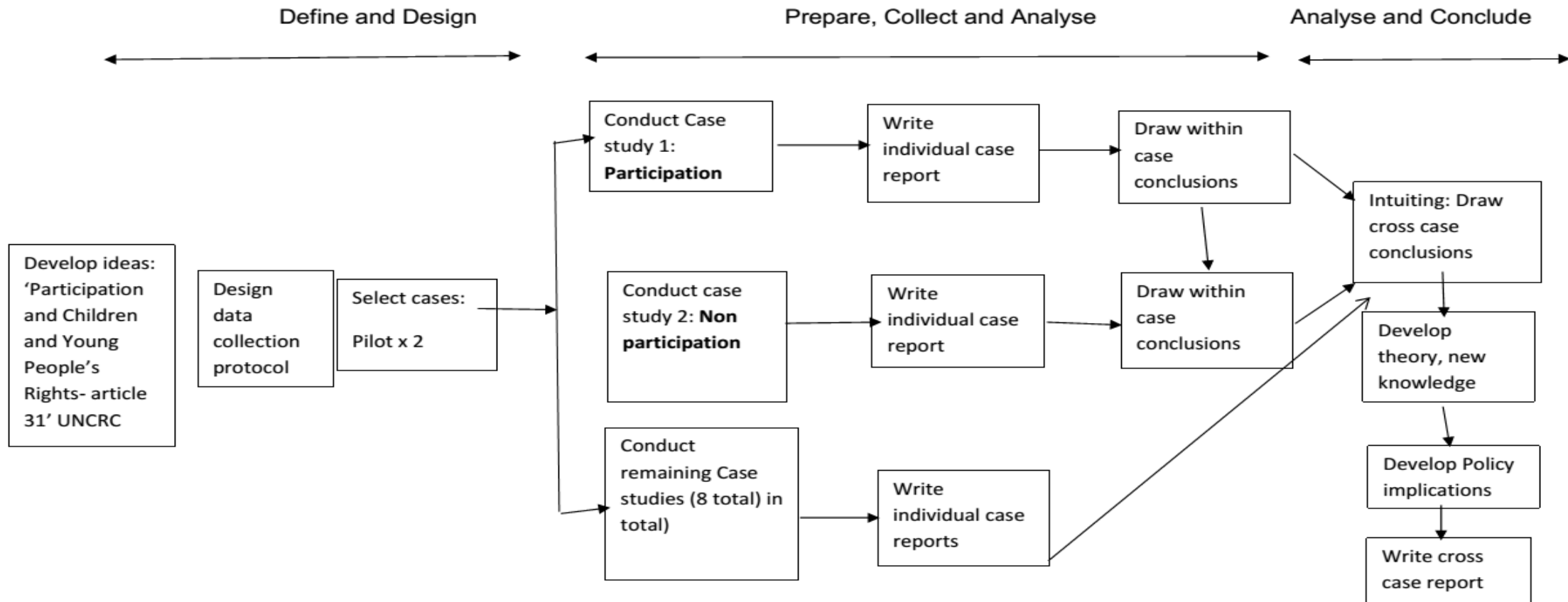


**Figure 1:** Predicted Gross Motor Function Measure (GMFM-66) motor scores as a function of age by Gross Motor Function Classification level. \*GMFCS levels with significant average peak and decline. Dashed lines illustrate age and score at peak GMFM-66.





## Appendix 2: Multiple Case study procedure adapted from Yin (2014) p 60



- 'Gillick' competency – Assent (Thackeray, 2017).
- Challenge of consent, anonymity and confidentiality- celebrate their enjoyment/ social media- 'ethical covenant' (Prosser, 2013).
- Facial expression sometimes missing, other cues from their interaction with equipment and environments.
- Parental consent.
- Data collected from March 2017-March 2018



# Method: Interviews using Symbolic play and Drawings

## Symbolic and sensory play to engage in story

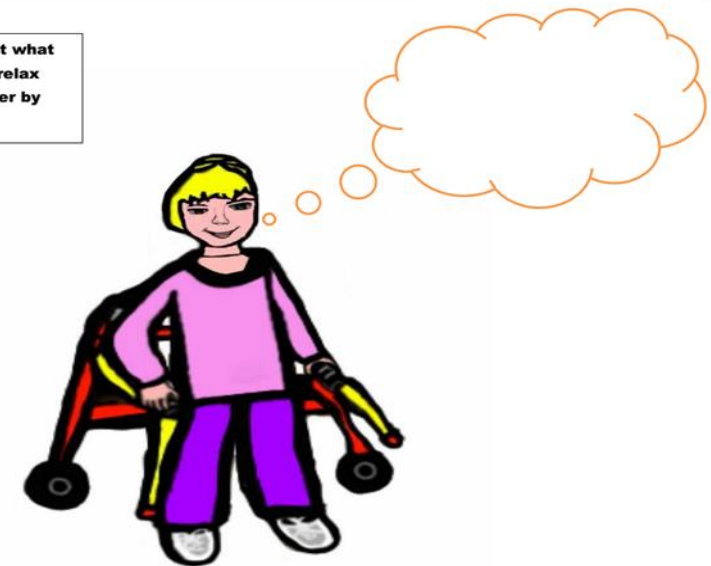


## Drawings (Pickering and Pickering, 2015)

Hussain is thinking about what he would like to do to relax and play can you help him by adding your ideas?



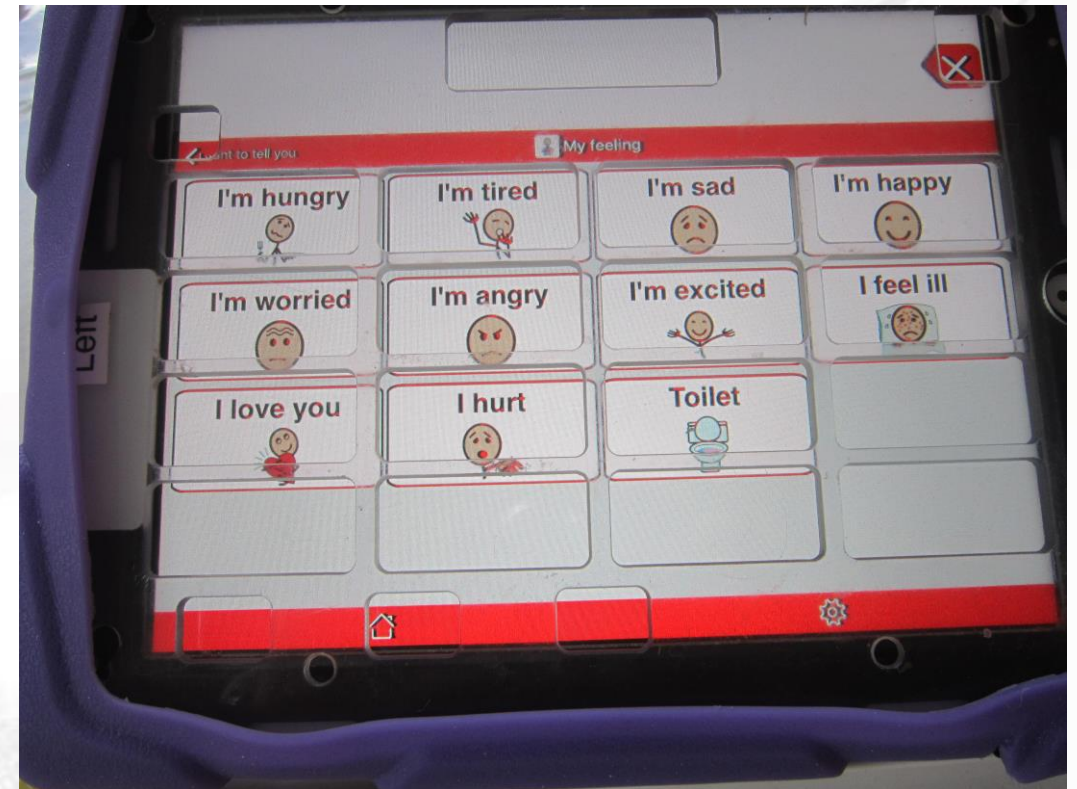
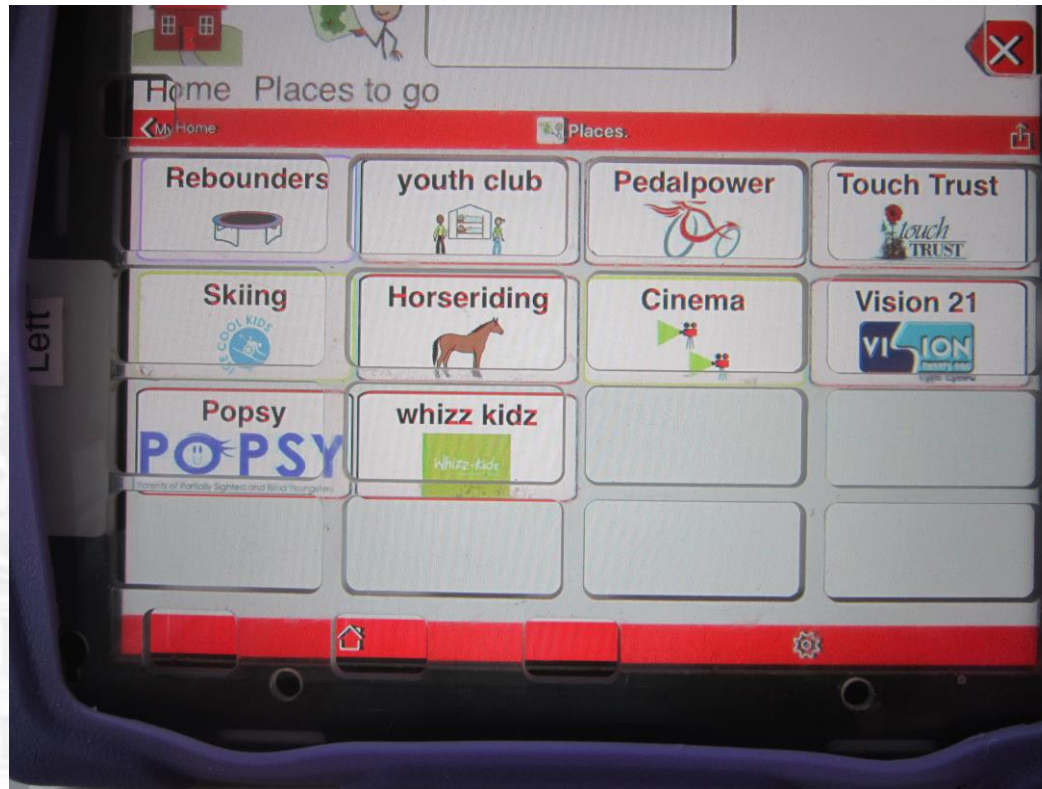
Natalie is thinking about what she would like to do to relax and play can you help her by adding your ideas?



# Method: Interactive interviews with Children and young people: iPad

Lily May 16 years: Experiences and choices

How I feel



I was asked 'why I am doing this research?' via the iPad with a key guard



Clare 9 years (GMFCS IV): Experiences and choices : I want to ride my bike.....



Limitation:

'Views' difficult to explore further when participants using a communication aid



*“....That was a really amazing day (aged 2 years) because I suddenly thought wow she can cycle, if you've got the right equipment, you can do practically anything as long as you can find the right equipment. Because up until then I kind of thought it's such a small world, you can't do anything and then suddenly I thought, right if we've got the right equipment, the world's our oyster we can do it.....”*

**Anonymity: Unable to see joy on her face**



**Matthew (14 years) : Skiing-**  
**[www.icecoolkids.org](http://www.icecoolkids.org)**

**Surfing-[www.surfabilityukcic.org/](http://www.surfabilityukcic.org/)**

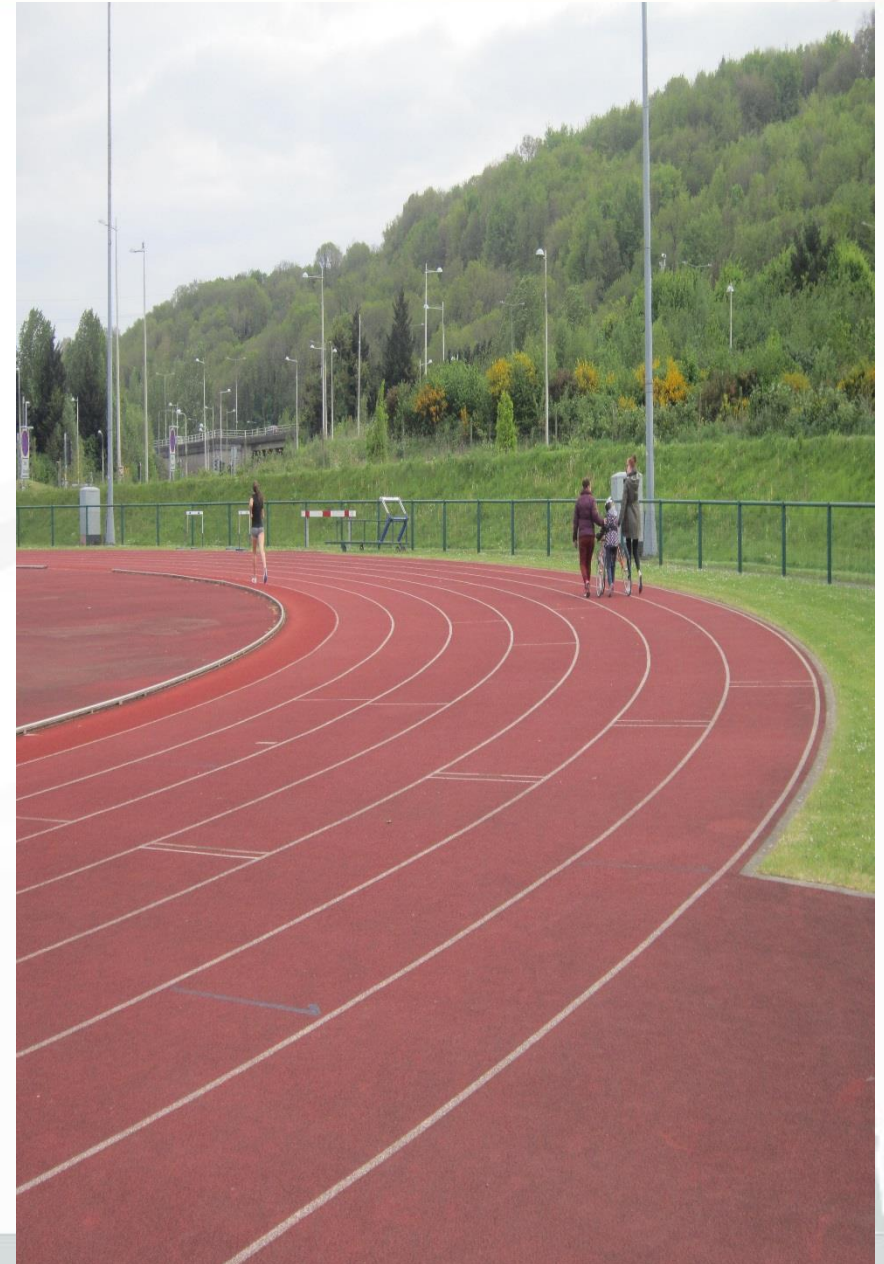


# Nick (14 years) Race Running observation indoor and outdoor



Race Runner used by Nick

Would the spinner toy identify him?





# Eye Gaze technology –pre-linguistic choices ‘Poppy’ (9 years)

## Participation ‘on own’



# Bree: Touch Therapy/ Brownies



# Music as a language- creativity- each instrument played in interview 2



- Gastrostomy feeding in public places-surviving
- Play scheme 'normalised' this behaviour as other parents carrying out feeds



# Interactive museum: Sensory experiences



# Thriving- James (14) enjoying ice cream and cone, bowling



# Visual views of what participants can see: James and Poppy

Heights of fences

Big Wheel, Winter Wonderland

Transparent lift in indoor  
museum



I have socially constructed their stories by including the visual to provide context of equipment and environments that support their participation: Innovation

Is the way I have utilised the visual data authentic to represent their views, experiences and choices? Could I have described the event to portray the same meanings?

Working with analysis of data to explore theoretical ideas.





# Questions ?

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Supervisory team: Dr Paul Gill, Dr Carly Reagon and Dr Jane Davies

Dawn Pickering, Staff PhD Candidate,  
Cardiff University's School of Healthcare Sciences;  
[pickeringdm@cf.ac.uk](mailto:pickeringdm@cf.ac.uk), Twitter: @DawnMPickering